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AUTHOR Wright, Beatrice A.
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ABSTRACT

Five myths regarding physical disability are examined. First, the myth that people with physical disabilities tend to be more maladjusted than the ordinary person is analyzed, and it is concluded that the common association between maladjustment and physical disability is grossly oversimplified. Second, the myth portraying people with disabilities as leading tragic lives is noted. The myth of excessive frustration is seen as the third myth, and reasons for the existence of this myth are considered. A fourth myth, that the environment does not contribute to disability, is noted. The final myth explored is the myth that the disability is a punishment of evil. The implications of the need for blame are examined. (CL)

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Disabling Myths about Disability

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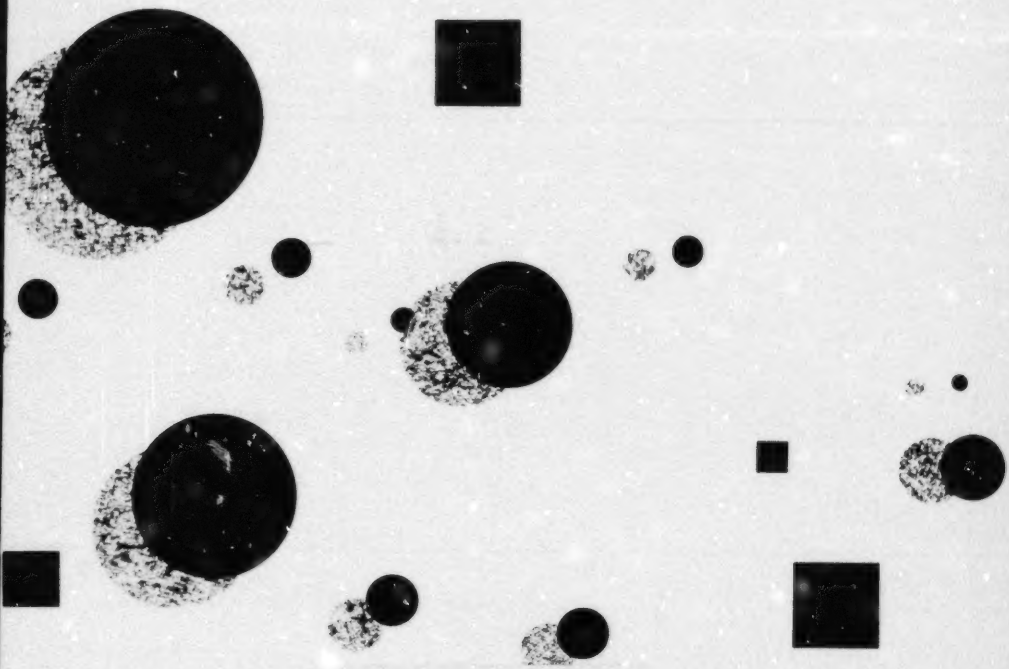

by Beatrice A. Wright, Ph.D.

Some convictions are held not necessarily because people like them, but because they seem so necessarily true. They can be figments woven out of our own habits of thinking and feeling, but when they get in the way of allowing human potential to flourish, they must be examined and counteracted. These myths can be so compelling that both laymen and experts succumb to their power and either ignore facts that belie them or distort facts to fit them. What are some of these myths? From where do they get their force? What mischief do they create?

The Myth of General Maladjustment

The first of these is "the myth of general maladjustment." In essence it states that people with physical disabilities tend to be more maladjusted than the ordinary person. Aphoristically you hear it as "a twisted mind in a twisted body." But what are the facts?

There are literally hundreds of studies dealing with this question; yet the results, no matter how they are ordered, cannot be made to favor the group without disabilities with even moderate consistency. To be sure, some studies show that persons without disabilities have more mature and constructive personalities, but other studies show the reverse. It is true that a sheer frequency count would yield a large number of studies in the column favoring people without disabilities, but typically the results of such studies can be attributed to experimental artifact if not artifice.

Too many studies, for example, use tests and measures whose interpretation must be vastly different when applied to persons with particular disabilities. You can see that an affirmative answer to the question, "Do you hesitate to introduce people at a party?" would have a different meaning when given by a person with deafness than by a person with normal hearing. Yet, such differences in *interpretive* significance have too often been ignored. When a number of such invalid questions contaminate the experiment, the presumed result that persons with deafness are more maladjusted than those with hearing may indeed be an experimental artifact.

Dr. Wright is professor of psychology at the University of Kansas, Lawrence. She is a former member of the Professional Advisory Council of the National Easter Seal Society.

"Most persons with physical limitations make about as good (or as poor) a personality adjustment as do those without physical limitations."

Then there are studies comparing the adjustment of persons with disabilities and those without that ignore the possible influence of factors, other than disability, that distinguish the two groups. For example, one study investigated the adjustment of college age, but noncollege attending, "crippled girls" in a charity camp by comparing their scores on a questionnaire with those of female college freshmen on whom the questionnaire was standardized. The former group was found to rate more emotionally maladjusted. In the wisdom of detached critical appraisal, we can immediately point out that the difference in scores may plausibly be accounted for in terms of differences between the two groups other than physical disability. It is important to note that girls attending a charity camp are quite differently selected, aside from their disability, from college freshmen. They may be expected to differ in socio-economic status, education, and personality on this basis alone.

One effective antidote to confusing the effects of other factors with disability is to entertain the "something-else-perhaps" query as a check on the "nothing-but" dogma. Instead of attributing the low adjustment scores of the girls in the aforementioned study to "nothing but" the disability, this notion becomes as tenuous as quicksilver as soon as one introduces the possibility that perhaps something else may be held accountable. So it is that the insightful parent, teacher, and rehabilitation worker have learned to avoid the error of reducing all difficulties of the child to the fact of the child's disability by considering an array of possible contributing factors not all of which are even connected with the disability.

There are other methodological pitfalls that have weakened the studies purporting to demonstrate the maladjustment of persons with disabilities. At this time it can be said with considerable assurance that the great overlap in the level of adjustment of persons with and without disabilities is at least as significant as the relatively small margin of difference found in some of the studies. Most persons with physical limitations make about as good (or as poor) a personality adjustment as do those without physical limitations.

We can now inquire into the basis for the myth of heightened maladjustment and why the myth persists in the face of a lack of evidence to support it. One of the main factors has been called the "halo" or "spread" phenomenon. Briefly, this means that, where a dominant characteristic of a person is negative, he or she will tend to be

perceived negatively with respect to other characteristics as well, a parallel proposition holding for positive characteristics. Thus, a single fact of crippling tends to generate in the mind's eye the notion that the person is also less able mentally and less sound emotionally.

Since the spread phenomenon occurs unconsciously, we would expect it to have greater reign under conditions of heightened emotionality. That is why, aside from matters of disability, the positive halo so easily prevails when love is new and negative distortion spreads with our enemies. That is also why the myth of heightened maladjustment thrives when we have deep fear, resentment, or guilt regarding disability.

Sometimes the spread phenomenon is even fed by personal advantage. It is not hard to see the role of personal motivation in underscoring the worst traits of one's enemies. In the case of disability, however, the motivation factor is often more covert, for to want to see a person with a disability in a bad light is morally indefensible. And yet such a wish hides behind the demeanor and behavior of people more often that we like to think. It has been labeled "the requirement of mourning" when people need to reassure themselves of their own status and well-being by insisting that the person with a disability is a suffering and unfortunate creature. The insistence is poured with an oozing pity that insidiously spreads the negative effects of disability. Persons with disabilities and those close to them, such as parents and spouses, have met this devaluating pity in the figurative pat on the head and the crocodile tears that say, in effect, "Look how fortunate I am in comparison to you." Genuine sympathy is one thing; devaluating pity, another.

The wish to emphasize the negative effects of disability and imagine them when they don't exist is also seen in some rehabilitation workers who need to reassure themselves of the importance of their services and thereby of themselves. These workers tend to view their client as a child—helpless, defenseless, and vulnerable—and by their behavior will keep the client in a subordinate position. Even parents and persons with disabilities themselves are not immune from the wish to make the worst case possible out of disability, for this wish can reflect the martyr complex, the need for self-pity, the need for self-punishment, and other needs in the search for secondary gains.

"A human being is not an inanimate object, becoming more and more scarred with each successive blow."

I do not want to leave the impression that undue emphasis on the negative effects of disability always implies a wish to see the

person with a disability in a bad light. We all know that when we are genuinely interested in someone, we become concerned about any matter that is troubling, such concern often tending to exaggerate the significance of the difficulty. Thus, parents and teachers sometimes see the child primarily in terms of his or her shortcomings—that fact that he or she is poor in arithmetic, or lazy, or poorly coordinated—without permitting the child's strengths to help draw the proper perspective. The shortcomings are immediate and demand our attention; as such, they loom large. The good points are not troubling; as such, they tend to recede into the background.

The question still remains, however, as to how people with a disability achieve more or less the same level of adjustment as their counterparts without a disability. The explanation requires recognition of several factors. First of all, all human beings know rejection and frustration, disability being only one variant among many that contribute to social and personal difficulties. Second, negative psychological situations are not the only ones experienced by a person with a disability. Certainly respect, encouragement, and acceptance from family members and friends, from self-help and other groups, are not infrequent, and such interpersonal relations may well provide the main prophylaxis against the destructive personality effects of devaluation from others. Even the larger society looks up to a person who achieves in spite of disability. Third, a society that gives weight to the dignity and value of each of its members facilitates adjustment by providing education, work and recreation outlets, and other means that will meet the needs of persons with special problems. The fourth point is perhaps the most important of all: a human being is not an inanimate object, becoming more and more scarred with each successive blow.

". . . the common association between maladjustment and physical disability is a grossly oversimplified myth unwarranted by the facts."

For clarification, let us consider the relationship between *degree* of disability and adjustment. One might assume that the more severe a person's disability, the more difficult it is for the person to accept it or to achieve good adjustment. But the facts provoke serious question of this. Though some studies have shown a relationship between degree of disability and poor adjustment, other studies have shown no relationship, and still others have shown the reverse relationship.

To explain these inconsistencies, it may be postulated that persons with mild disabilities may, because they are *almost* "normal," have a greater need to hide and deny their disability, thereby thwarting

their own adjustment. Persons whose disabilities are so severe as to be undeniable have little recourse but to grapple with the problem of accepting themselves as persons with a disability. On the other hand, it may also be postulated that a mild disability, by imposing fewer frustrations owing to the barrier of physical limitations, should make adjustment easier. Doubtless there are still other factors associated with degree of disability, some favoring and some hindering good adjustment, the resultant effect being quite removed from the objective fact of severity. Notice that we have moved from the physical fact of degree of disability to *psychological* concepts, such as the need to hide the disability and the need for genuine self-acceptance, in order to help account for the experience and behavior associated with a disability.

In any case, the individual actively works on his or her unique problems, reorganizing his or her own outlook and influencing environmental supports in order to some extent to control one's own destiny. The success of this continuing process is simply unpredictable from the sheer fact of physical disability. Neither do such refinements as the duration, kind, or severity of disability help the prediction. We can only conclude that the common association between maladjustment and physical disability is a grossly oversimplified myth unwarranted by the facts. This is not to say, of course, that people with a disability are generally well-adjusted any more than one could say this about the population at large. All that can be said is that physical disability is an extraordinarily poor criterion for judging the mental health of an individual or a group of persons.

The Myth of Tragedy

The second myth is "the myth of tragedy." It appears when the life of a person with a disability has been made equivalent with disaster, when there has been such a coalescence between tragedy and disability that nothing else is perceived but a life filled with suffering, frustration, and rejection.

The dictionary defines tragedy as involving "a fatal outcome of a hopeless struggle or at least subjection to extreme and protracted suffering, especially of a mental sort." If cerebral palsy, mental retardation, deafness, and blindness, for example, are tragedies, how can we convey to people with these disabilities, or to their families, that their lives can be rewarding, that they can partake in meaningful activities, that not all of life is disability-connected? These hopes are realities and are not compatible with the perception of disability as involving a fatal outcome of a hopeless struggle. The less severe view

of tragedy that defines the suffering as extreme and protracted might be applicable were it not for the fact that the modifiers "extreme and protracted" tend to be extended indefinitely in degree and time so that virtually all of life for all time is reduced to tragic aspects.

There are very few people who like to be looked upon as tragic, and those who do are accused of wallowing in self-pity or exploiting their disability. One might be willing to accept a particular *event* as being tragic, as when a loved one dies or when a crippling disease strikes, for this gives recognition to the great suffering and loss that is experienced. Even then, the person needs and wants help in realizing that the tragic impact will dissipate in time, that mourning is confined to a period of mourning and not to a whole lifetime. The tragic appellation *must be confined to be tolerated.*

Persons with disabilities who have begun to accept the fact of disability without the suffering of shame see life as encompassing far more than those experiences that are blocked by their disabilities. If indeed they felt that only through physical "normalcy" could worthwhile things of life be gained, then they would feel the tragedy of their fate and succumb to either abject resignation or active self-pity. Or if they continued to contrast their existing state with an idealized and mythical "what might have been" or "what should have been," then the negative aspects of their situation would remain in focus.

"Persons with disabilities who have begun to accept the fact of disability without the suffering of shame see life as encompassing far more than those experiences that are blocked by their disabilities."

But the great majority of persons with disabilities, even those with severe disabilities, have not allowed the disabilities to overshadow everything else. They have refocused their values so that the disabling effects of disability become more closely confined to objective limitations instead of engulfing all meaningful experiences. In the process, physique becomes subordinate to other values, and the things the person can do become open to pleasure and satisfaction.

It is understandable, then, that persons with disabilities resist, if not resent, being considered tragic figures. They resist, if not resent, their life being dismissed as a tragedy, for the designation implies the futility of their efforts at reevaluation of what has to be faced. It undermines their struggle to emphasize the positives in their life and threatens to make the negatives supreme. To persons who have accepted their disability, the disability is not a tragedy entailing unabated mental

suffering. Such acute suffering may be characteristic of a "period of mourning," but this is just one phase of the adjustment process known as "acceptance of loss."

So it is with parents who have accepted and adjusted to their child's disability. They do not continue to suffer the mental anguish of tragedy. They can and do find gratification in helping their child lead a purposeful life, and life begins to encompass not only suffering and despair, but also accomplishment and satisfaction. The suffering and the satisfaction seem to oscillate, to come in waves, for acceptance of the child's disability is not an all-or-none process. The struggle to accept proceeds even though at another layer of the personality the parents may still resent the disability and continue to experience distress over the loss of important values now denied the child and the parents. But the distress does not remain as *the* characteristic of the parents' or child's lives. It becomes tempered by adjustive forces; the heavy burden of nonacceptance becomes lightened; the depressed moods becomes less intense, less protracted, and less frequent.

"... how unthinkingly we use the word 'tragedy' as an epithet even though its connotations run afoul of our intentions!"

In a certain sense, all of us might be ready to agree that cerebral palsy, mental retardation, blindness, and deafness are tragedies. But that sense must be carefully restricted to the time-bound deep experience of loss of important values when the person and his or her family are first faced with the impact of disability. Then it is that the loss aspects of the situation are necessarily in the forefront. In the case of loss of a loved one, all one can think of is the pleasure of sharing that will be denied forevermore. All one can think of in the case of disability is the pleasure of those aspects of life that one assumes are denied for all time. Nothing else matters. But this preoccupation with loss, with what "can't be had," "can't be done," "can't be enjoyed," and with what "might have been," dissipates with time. Gradually the person discovers meaning in what can be had, can be done, and can be enjoyed. Physical "normality" and its assumed benefits are no longer all-important.

A reevaluation of a basic and constructive nature is in the process. The new perceptions, vying with the old, are threatened by the insidious equation between disability and tragedy. Yet, how unthinkingly we use the word "tragedy" as an epithet even though its connotations run afoul of our intentions!

The Myth of Excessive Frustration

The discussion thus far should also cast suspicion on the commonsense notion that excessive frustration abounds in the lives of persons with disabilities. The little research there is indeed rejects this notion as a myth. When the lives of children with and without disabilities were systematically observed and evaluated according to the proportion of experiences that ended in frustration and failure on the one hand, or in satisfaction and goal attainment on the other, no difference was found between the two groups. The investigators concluded that the contention that motor disability necessarily implies more frequent occurrence of bad episode endings is simply not supported.

This does not mean that frustration is never tied to disability. Obviously this is nonsense. All this says is that having a disability does not mean that the person is subject to *more* frustration. The individual may be subject to more of *certain kinds* of frustration, but evidently becomes less exposed to other sources of frustration the net effect being a frustration level that in general approximates the usual. Certainly there are people with disabilities who are highly frustrated, but then there also are people without disabilities who are highly frustrated. A clinic or institution may tend to draw to its services the excessively frustrated and maladjusted, but such selection cannot provide the basis for generalization to the overall population of people with disabilities. Just as maladjustment does not show a progression with the fact or degree of disability, neither does the amount of frustration experienced depend on the fact or degree of disability.

". . . the presumption that disability brings about excessive frustration leads the observer to expect frustration, an expectation that conditions the observer to highlight evidence supporting it and to suppress or distort evidence conflicting with it."

It is well to examine the basis for the conviction that sees disability steeped in frustration. First of all, the person who is uninitiated into the specific ways of circumventing limitations, tends to perceive disability as an insurmountable barrier to the achievement of many goals. For example, many persons would be certain that the following activities are closed to those with blindness: playing ball, mowing the lawn, roller-skating, and so on, until the list becomes frighteningly long. It is with surprise and admiration that many learn that none of these activities is precluded, because the manner of carrying them out can be appropriately modified.

A second reason is that in empathy, we often react the way we think we would feel in the situation, without realizing that adjustive forces within our own psychic economy would so alter the meaning of the situation that the emotional reaction would correspondingly be different. The thought of taking so much extra time and energy to ascend stairs may be frustrating to the person without a disability, but to the person with an orthopedic impairment climbing stairs may signal satisfaction at having gained in independence.

Still another reason is the tendency to reduce to the fact of disability whatever frustrations and failures a person with a disability may experience, even though they may be only indirectly related or not at all. Such reduction is a consequence of the power of physique to control judgment through the spread phenomenon.

Finally, the presumption that disability brings about excessive frustration leads the observer to expect frustration, an expectation that conditions the observer to highlight evidence supporting it and to suppress or distort evidence conflicting with it.

Exploding the myth of excessive frustration does not mean minimizing the problems associated with disability. On the contrary, it forces us to recognize the effectiveness of environmental accommodations and of adjustive changes within each person. Examples of environmental frustration-reducing accommodations are:

1. Considerations in the home that take into account the special needs of each person

2. School curricula geared to individual and group differences

3. Architectural features that fit varying physical attributes of people

4. Legislation on behalf of persons with disabilities

5. Social attitudes of acceptance, etc.

Adjustive changes within the person that serve to reduce frustration center around *accepting the disability as nondevaluating* thereby allowing establishment of goals and patterns of behavior in accord with one's abilities.

"Environmental accommodations and personal adaptations are the two foci that must be counted on in the rehabilitation effort, and exploding the myth of excessive frustration gives reassurance that this trust is well-founded."

Frustrations that unjustly stem from attitudinal, legal, economic, educational, and architectural barriers must be identified so that these frustrations are not falsely attributed to the nature of the disability itself. Efforts to reduce frustration can then be directed toward actual sources of frustration; these typically require environmental change and not only change within the person. Environmental accommodations and personal adaptations are the two foci that must be counted on in the rehabilitation effort, and exploding the myth of excessive frustration gives reassurance that this trust is well-founded.

Exploding the myth of excessive frustration does not mean minimizing problems associated with disability. Overcoming problems and reducing frustration have value, *not* for the purpose of eliminating frustration from the lives of people, but to enable the person to undertake new challenges that will involve new frustrations.

It should also be understood that the amount of frustration cannot determine issues of justice and human rights. Injustice may be great when frustration is high or low. Many institutional environments are not especially frustrating, but neither are they conducive to human development. Resigning oneself to difficult circumstances may reduce frustration, but may also mean resigning oneself to injustice. Raising consciousness and expectations often increases frustration in people who previously had "known their place."

"Frustrations that unjustly stem from attitudinal, legal, economic, educational, and architectural barriers must be identified so that these frustrations are not falsely attributed to the nature of the disability itself."

The Myth of Personal Attribute Alone

The point stressing the importance of appropriate environmental conditions serves to expose the myth that a disability is primarily a property of the person. What limits a person, however, is not only the person's own disabilities, but also the environmental restrictions imposed by attitudinal, architectual, legal, and other barriers. To say that a person can't get into a building because he or she has a physical

disability is only part of the story. A vital part has been left unsaid—namely, that the person can't gain entrance because he or she is architecturally handicapped. It is well to remember that a disabling condition is usually as much an attribute of the environment as of the person, and often more so.

Research has revealed the interesting fact that people (the insider) are more likely to perceive the environment as an important source of

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their own difficulties than is someone who does not share those difficulties (the outsider). The reverse is true when it comes to perceiving difficulties primarily as an attribute of the person. That is, the outsider is more apt to attribute the main source of a person's difficulties to something about that person than is the person himself or herself. This difference can be partly understood in terms of the vantage point from which each appraises the problem. The insider is forced to become environmentally oriented as he or she strives to manage and modify the physical and social world in order more adequately to meet personal needs. The outsider, on the other hand, does not ordinarily focus on the environment when viewing another person. What draws the outsider's attention is the behavior of the other person, and since the behavior "belongs" to that person, the outsider seeks traits inherent in the person to account for the difficulties the person is having. Thus it is that the ordinary outsider is more likely than the insider to attribute any real or imagined lack of accomplishment to limitations inherent in the person's disability, whereas the person with the disability is more likely than the outsider to feel that major sources of trouble reside in the physical and social environment. This orientation toward the environment provides a strong basis for encouraging involvement on the part of people with disabilities in action programs toward improving their situation.

The Myth of Sin

The last myth I should like to explore is the myth of sin. This myth has to do with the perceived cause of disability and implicitly affirms that disability is a punishment of evil, usually on the part of the person or the person's family, but sometimes on the part of others, such as the doctor. Because this myth is so easily challenged by the rational scientific view that regards the cause of disability as an amoral fact, it is more often expressed covertly in the shame or guilt and the need to blame that so commonly centers around disability.

An important basis for the myth has to do with the principle that a cause tends to be perceived as similar in kind to its effect, just as the imprint in the sand fits the shape of the foot that made it. Positive effects must have positive causes; negative effects must have negative causes. In the case of disability, amoral causality, being neutral, does not fit the perceptual requirements. To make the cause sufficiently negative to match the negative state of disability, it must be blameworthy.

Another aspect of the matching between cause and effect is known as the "just world phenomenon." It has to do with the need to bring harmony into one's world by aligning existing reality with what ought to be. In short, it is wrong for what is good to be harmed and for what is bad to be blessed. Such injustice is rectified either by changing the lot of the suffering person so that he or she no longer suffers or by assuming in some way that the person's fate is deserved. So it is that the myth of sin finds fertile soil in the event of disability. The disability is a reality. Especially where it is an unchangeable one, harmony is restored when it is felt to be justified punishment.

No one is completely immune from these forces, and the silent, often unconscious, accusation of the general public is one of the important barriers to understanding. Also, the person with a disability may feel guilty, although the content of the guilt may be vague. In less anguished form, self-accusation is seen when a person, beset with a series of misfortunes or continuing disablement, feels that "it is someone else's turn," as if he or she had suffered enough and paid all debts for any sin. Is not the person who asks the seemingly naive question "Why did this have to happen to *me*?" in some obscure way searching for a personal offense that might justify the hurt? A slight change in the question to "Why did this happen?" represents a major change in the meaning of the disability, a change in which objective, impersonal attribution is uppermost and guilt less potent.

"No one is completely immune from these forces, and the silent, often unconscious accusation of the general public is one of the important barriers to understanding."

In some instances the source of the disability may be attributed to the negligence of a second person, in which case it is often felt as willful negligence even though objective consideration may deny premeditation. Imputing an intention augments the wrongdoing to a level appropriate to the misfortune.

Thus, hardly a parent of a child who has a disability can escape being bothered by the thought that in some way avoidable mismanagement was a contributing cause if not *the* cause of the disability.

The mother may blame herself or her doctor for the sedation that might have caused the birth injury of her child. The father may blame himself for the accident that occurred, or he may blame others. Someone has to be blamed, for disability is perceived as having its source in wrongdoing.

It is important for the person, the person's family, and the wider public to become aware of the need to blame, why it is psychologically so pressing, for the insight will help in viewing disability as an amoral fact and the person with a disability as being capable not culpable, whose problems must be met and worked through so that life can continue to unfold worthwhile experience.

There are many other myths that should be challenged. The five that have been selected—namely, the myth of general maladjustment, the myth of tragedy, the myth of excessive frustration, the myth of personal attribute alone, and the myth of sin—are among the most disabling, not only to the person with a disability and those close to that person, but also to the ordinary person who, by them, becomes ill-prepared to meet the challenge of disability.

You may have noticed that I have used the phrase "the person with a disability" rather than "the disabled person." The former, though more cumbersome, far more adequately expresses the enormously important fact that a physical disability does not necessarily, or even typically, disable the *whole person,* myths notwithstanding.

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national easter seal society
2023 West Ogden Avenue
Chicago, Illinois 60612

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